Young adult carers: the impact of caring on health and education

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Abstract

Research has shown that young people who care for parents and relatives (young carers and young adult carers) are at greater risk of mental and emotional difficulties and are more likely to do badly at school or college. To explore the difficulties faced by young adult carers (aged 14 to 25) in the UK, an online survey was conducted. Almost half (45%) of the 295 respondents reported having a mental health problem. The relationship between the extent of caring and perceived mental health problems, and the impact of caring responsibilities on work and education were investigated.

Keywords

Young Adult Carers; MACA; Mental Health; Education

Introduction:

Whilst it is usual for young people to help with housework and household chores, many young people under the age of 18 provide more intensive, personal and emotional care to family members. Many carry out work which would generally be considered to be the remit of health and social care professionals – tasks such as administering drugs, washing and bathing those they care for, providing emotional care (often to family members with diagnosed mental ill health) and managing the household. In the UK, these young people are referred to as 'young carers' and have been the subject of much research since they were first 'identified' by Becker and his colleagues in the early 1990s (Dearden and Becker, 1995, 1998; Aldridge and Becker, 1999, 2003). Research has shown that young carers are more likely than other young people of the same age to do badly at school or college (Frank et al, 1999; Moore, 2005; Moore et al, 2009), and to have mental and emotional difficulties (Aldridge and Becker, 2003). Since many young carers spend a considerable amount of their time looking after family members, it is not surprising that school work is neglected and their education can suffer.

Young carers are a global phenomenon and wherever researchers have looked, they have identified children and young people who have substantive caring roles. This includes European countries (e.g. UK, Norway, Sweden, Austria), the United States, Australia and New Zealand, Sub-Saharan Africa and the Middle East (Becker, 2007; Becker and Leu, 2014; Evans and Becker, 2009; Leu and Becker, 2017). Whilst the type of tasks they carry out may vary in some of the detail, the roles are similar from country to country (Evans and Becker, 2009; Hunt et al., 2005; Nagl-Cupal et al. 2014). Across the UK, official figures (UK Census, 2011) suggest that between 2% and 4.5% of children under 18 years of age are young carers. Many of these will

have taken on their caring role at an early age; Sempik and Becker (2013) reported that the mean age at which a sample of young carers at school started their caring role was 9 years. Support services are available and many young carers attend support ‘projects’ run by local authorities and charitable organisations. However, the support needs of a teenage adolescent are substantially different to those of a five or eight year old and support services generally address the different needs of different age groups through matched services. In 2008, Becker and Becker (2008) proposed that those young people aged14 to 24 who have caring responsibilities are a distinct group, this is now generally accepted and the term ‘young adult carers’ has been applied to these young people. Whilst there has been much research on young carers (those aged under 18), there has been little work on those aged 14 to 24. However, this group of young people is at a point of transition – from school to college or university, and then on to employment. Additional stress and distraction at the time when many are taking exams or making decisions about their future careers are likely to influence outcomes in a negative way.

Methods:

An online survey was created to explore the perceptions and experiences of young adult carers (aged 14 to 25) living in the UK with regards to their health and their experiences of education. A simple web page was created which briefly outlined the objectives of the study and which linked to the survey (further information regarding the survey was provided within the survey itself). A distinctive domain name was chosen and registered (YACSurvey.com) and this was used to promote the survey through a network of young adult carers' support projects and events. The survey included the *Multidimensional Assessment of Caring Activities* (MACA) (Joseph et al, 2009a, 2009b) to examine the extent of caring activities carried out by the respondents. This is an 18 item questionnaire that provides a score for the total extent of caring, in addition to scores for six sub-dimensions of caring activities.

Responses to the survey were downloaded as a *Microsoft Excel* spreadsheet and then prepared for analysis. IBM SPSS Statistics (ver. 22.0) was used to provide descriptive and inferential statistics, including mean and standard deviation (values for standard deviation are shown in parentheses in the text). The following statistical tests were used: bivariate correlation (Pearson's coefficient and Spearman's rho); Chi Square (χ^2) with continuity correction for 2 x 2 tables where necessary; ANOVA with Tukey's HSD *post hoc* test; Student's t test; and logistic regression as appropriate. The level of statistical significance was set at $p < 0.05$.

This work was commenced when both authors were members of the School of Social Sciences, University of Nottingham and the study was approved by the ethics committee of the School.

The Sample:

A total of 295 respondents provided complete or partial data that was valid for inclusion in the analysis. There were 62 (21%) Males in the sample and 231 (78%) females; 2 (0.7%) respondents declined to give their gender. The overall mean age was18.8 (± 2.9; n = 284) years; and there was no statistically significant difference between the mean ages of males (18.1 ± 2.9; n = 56) and females (18.9 ± 2.9; n = 226); [t (280) = 1.751; p = 0.081].

The mean age they started caring was 10.2 years (± 3.9; n = 220); there was no significant difference between males (10.4 ± 4.0; n = 51) and females (10.1 ± 3.9; n = 167) in the age they started caring [t (216) = 0.535; p = 0.593]. Sixty one (25%) attended school, 75 (31%) were at a college of further education (which offer vocational and specialist qualifications, generally for 16-18 year olds) or in training; 31 (13%) were at university; 39 (16%) were in work; and 38 (16%) were not in education, employment or training (NEET).

One hundred and fifty four participants (52%) cared for their mother; 41(14%) cared for their father; 12 (4%) cared for both parents; 63 (21%) cared for siblings or step-

siblings and 12 (4%) cared for grandparents. Two hundred (68%) cared for one person; 72 (24%) cared for two people; 10 (3%) cared for three people; and 13 (4%) cared for four or more (n = 295).

There was no association in the number of individuals cared for and gender (Fisher's exact test, p= 0.902); or institution attended i.e. school, university, work or NEET (Fisher's exact test, p= 0.829). Similarly, there was no difference in the mean ages of those caring for one, two, three or four or more individuals [F (3) = 1.572, p = 0.196].

The difficulties of those cared for were as follows: physical disability 163 (55%); long term illness 139 (47%); mental ill health 144 (49%); learning disabilities 69 (23%); older people 34 (12%); and dementia 13 (4%). One hundred and forty eight (61%) of the 244 respondents who provided an answer were currently attending a support project for young adult carers or young carers; and 194 (80%) had attended a young adult carers or young carers project in the past.

Two hundred respondents provided details of their ethnicity; of these 175 (88%) were 'White British'; 5 (3%) were 'Black British' and 6 (3%) were Mixed Race/Black British; 6 (3%) were 'Asian/Chinese British'; 2 (1%) were 'Romany British'; and 6 (3%) were 'Other White European'. Overall, there was an insufficient number of those who were not 'White British' for any analysis with regards to ethnicity.

Results:

Level of caring

Overall, the mean MACA score of the whole sample was 18.1 ± 5.7 (n = 270), indicating a *'very high amount of caring activity'* (Joseph et al, 2009a). The MACA subscales showed that the greatest level of care was provided in the domains of emotional and domestic care, and the least in financial and practical aspects.

A comparison of male and female scores showed that females had a significantly higher total MACA score than males (18.7± 5.7 compared with 16.2 ± 5.3); and that they scored significantly higher on the MACA subscales of domestic, personal, emotional and sibling aspects of care (MACA scores are shown in Table 1). There was a significant (p = 0.001) but weak positive correlation between age and MACA score (Pearson's R = 0.2).

ANOVA showed that there was an overall significant difference in mean total MACA scores between groups attending different institutions (i.e. school, college etc) [F (4,238) = 2.960; p= 0.021]. Those in work had the highest mean MACA score (20.1 ± 5.8). Those at school had the lowest (16.5 ± 6.1). The difference between these two groups was statistically significant (Tukey's HSD, p = 0.008); there were no significant differences between any of the other groups.

Perceived Health

Two hundred and eighty five (285) participants provided responses regarding perceptions of their own state of health. Only 14% considered their health to be '*Very good'*, and 48% thought it was *'Good'*. However, 33% considered it to be *'Just OK'*, and 5% viewed it as *'Poor'*.

Just under two thirds (65%; 186/285) of respondents, overall, reported that they had one or more disabilities or difficulties. Forty five per cent (45%; 129/285) reported that they had a mental health problem. Examples of mental health problems were given to respondents in the questionnaire, and these included: 'anxiety, depression, bipolar and eating disorders'. Female respondents were more likely to report having a mental health problem than male respondents; 47% of females reported having a mental health problem compared with 30% of males (109 of 226 compared with 18 of 57, respectively). The difference was statistically significant; χ^2 (1, n = 283) = 4.451, p= 0.035. There was no significant difference in total mean MACA score between those who reported a mental health problem (17.6 ± 5.3; n = 123) and those who did not (18.5 ± 6.0; n = 147); t (268) = 1.369; p = 0.172.

Those who reported poorer physical health were much more likely to report having a mental health problem than those who whose health was better. 65% (70/107) of those whose health was 'Just OK' or 'Poor' reported having a mental health problem, compared with 33% (58/178) who gave their health as 'Very Good' or 'Good'; χ^2 (1, n = 285) = 27.812, p< 0.001. Those who were caring for a person with mental health problems were also more likely to report having a mental health problem themselves; 52% (75/143) compared with 37% (53/142); χ^2 (1, n = 285) = 5.990, p= 0.014. A slightly higher percentage (50%; 57/94) of those who cared for more than one person reported having a mental health problem compared with those who only cared for one person (42%; 81/191), however, the difference was not statistically significant; χ^2 (1, n = 285) = 1.177, p= 0.278. Age was not associated with the reporting of a mental health problem – there was no significant difference in mean age between those reporting a mental health problem (18.9 ± 2.8; n = 126) and those not (18.7 ± 3.0; n= 158); t (282) = 0.652; p = 0.515).

A logistic regression model was then used to explore the extent to which the variables listed above (age, gender, perceived physical health, caring for someone with a mental health problem, caring for more than one person) were predictive of reporting a mental health problem. In this model, the MACA sub-scores indicating '*Domestic'*, '*Emotional'*, '*Financial & Practical'*, '*Household'*, '*Personal*' and '*Sibling'* dimensions of caring activities were used to see whether any specific aspects of caring were associated with the reporting of mental health problems (as mentioned above, there was no significant association between *total* MACA score and the reporting of a mental health problem). The logistic regression model was statistically significant (χ^2 (11, n = 254) = 47.056; p < 0.001) and explained 23% of the variance

(Nagelkerke R Square). Gender and perceived poor physical health were significant predictors of reporting a mental health problem with odds ratios of 2.4 and 3.9 respectively. The MACA *Personal* care subscore was also a significant predictor (p = 0.008). However, the odds ratio was 0.82, indicating an inverse relationship i.e. a higher MACA score being indicative of a lower likelihood of reporting a mental health problem. These results are shown in Table 2.

Experiences of Education

Perceptions of School, College and University

Of those respondents still at school, around half 48% (28/58) enjoyed school; and 78% (46/59) thought they were doing well. Of those who had left school, 42% (58/137) reported that they had previously enjoyed school and 60% (77/136) thought they had done well, although 45% (60/134) considered that they could have obtained better grades had it not been for their caring role. A greater percentage of those at college or university (79%; 72/91) reported that they enjoyed the experience; and 70% (62/90) reported that they thought they were doing well (a similar percentage to those at school). Overall, 40% could think of a particular person who had helped them at school; and 31% reported being bullied at school because of their caring role. At college or university the figures were 46% and 6%, respectively, for support and bullying.

Impact of Caring on Education

Table 3 shows the mean reported number of days of absence and the frequency of having to leave early or being called away because of caring duties. On average, those respondents at colleges of higher education or university missed the most days, around 2.5 days in the previous fortnight. One-way ANOVA showed that the difference between groups was statistically significant (p= 0.001); [F (3,153) = 5.629; p= 0.001]. *Post hoc* (Tukey's HSD) tests showed that the mean number of days of absence of those in higher education was significantly greater than that of any of the other three groups (vs school p = 0.001; vs FE and training p = 0.010; vs work p = 0.018). There were no significant differences between any of the other groups (p> 0.05).

Those in higher education reported having to leave early more often than those at other institutions and those at work reported being late as a result of caring more frequently than those in the other groups. However, one way ANOVA showed that there were no significant differences between groups for these and any of the other measures of attendance (p> 0.05).

Analysis showed that the degree of absence and lateness was associated with the level of caring responsibilities (i.e. MACA score). There was a weak to moderate positive and statistically significant correlation between the total MACA scores and the measures of absence and lateness. Calculated Spearman's rho was 0.3 (0.30 – 0.34) for each of the four measures ($p < 0.001$); hence, the greater the caring responsibilities, the greater the impact on attendance.

Fifty five percent (51/93) of those at college or university reported that they had difficulties as a result of their caring role, and 17% (15/90) were concerned that they would drop out as a result of their caring responsibilities. Those who were experiencing difficulties had a significantly higher mean MACA score than those who were not; 19.5 (± 5.5, n=51) compared with 16.9 (± 4.8; n=30); $t(79) = 2.124$; $p=0.037$.

Thirty eight respondents had previously been to college or university. Of these only 26 (68%) had completed their course; 11 (29%) had dropped out because of their caring responsibilities and one was unsure of the reasons for leaving.

Limitations

Our study was based around an online survey. It is possible that some young adult carers did not have access to the internet and so were excluded from the study. Others may have been put off by the web-based format or the length of the questionnaire and may have responded better to an interviewer. However, 295 young people did respond to the survey and provide data suitable for analysis.

It is important to note that this was a cross-sectional study, and whilst we have showed associations, for example, between the reporting of poor physical health and mental health problems, we are not able to attribute causality. Further work is needed in this respect using other research approaches in order to establish the prevalence of mental health problems among young adult carers and to explore the nature and causes of such problems.

The sample was obtained primarily through young adult carers support projects and networks, and so may not be representative of the population of young adult carers as a whole. However, not all of the respondents currently attended a project, and some had never attended one, so the study sample was not wholly comprised of those who attended support projects.

There was not an even distribution of levels (i.e. MACA scores) of caring across respondents in the sample. Those with high caring responsibilities appear to be over-represented. This may have made it more difficult to see associations between different levels of caring and other outcomes. However, those with low levels of

responsibilities may be unlikely to seek (or, possibly, need) support from young adult carers projects or attend young carers events and hence would not have been sampled by our method.

Estimates of days lost and number of times late relied on individual recall and therefore may be subject to inaccuracy. Reporting of mental health problems relied on a single question and did not distinguish between different conditions or severity. However, for a respondent to report such a problem suggests that the young person is experiencing some level of distress that is causing them concern.

Discussion

Our sample of young adult carers had a higher percentage of females (78%) than males suggesting that more young women than men have caring responsibilities. It is important to note that ours was not a random sample but recruited through (and publicised by) support projects for young adult carers. Hence, the demographics of the sample may not necessarily reflect the true demographics of the population of young adult carers. However, previously published research in a random sample of 10 to 14 year olds in Austria (Nagl-Cupal et al, 2014) showed that around 70% of young carers were female. Data from the 2011 UK Census suggest that, overall, the percentage of young males and females carrying out caring tasks is approximately equal. However, closer inspection of the data reveals that as age and time spent caring increase, young women become over-represented. For example, in the 20 to 24 age group, 0.9% of females provided 50 hours or more of care per week compared with 0.5% of males. This compares with 0.4% and 0.3%, respectively, for the 16 to 17 age group (Census, 2011). This is consistent with our findings that among young adult carers, the extent of caring (as measured by the MACA) is higher in females than in males.

More research is needed on this issue, to explore whether, for example, a young female is seen as the ‘natural’ carer when there is a choice between siblings; and whether there is a transition in the caring role from a male to a younger female sibling as the female gets older and is capable of assuming that role.

In our survey of young adult carers, we asked the following question: “Do you have any mental health problems (for example, anxiety, depression, bipolar, eating disorder)?” We were enquiring whether the young people were suffering any form of psychological distress or difficulty (whether caused by caring or not) that could impinge upon their daily lives. It was beyond the scope of this study to differentiate between different conditions and severities or to identify specific psychiatric disorders. Michaud and Fombonne (2005) suggest that: “*Although mental disorders reflect psychiatric disturbance, adolescents may be affected more broadly by mental health problems. These include various difficulties and burdens that interfere with adolescent development and adversely affect quality of life emotionally, socially, and*

vocationally" (Michaud and Fombonne, 2005; p. 835). Therefore, in our study, by using a single general question, we have attempted to gauge the number of young adult carers affected by this broad range of problems (these will also include a small number with more serious psychiatric disorders), and we then have looked at any potential associations between caring activities and the reporting of 'mental health problems' that may be worthy of further investigation.

The number of respondents who reported physical and mental health problems suggests that many young adult carers are in a poor state of health and wellbeing. There was a highly significant association between the reporting of physical poor health and mental health problems. This may be indicative of the substantial general distress felt by these young people in the different dimensions of their lives. The reported mental and physical problems of these young carers may also represent a general vulnerability of their families, and be indicative of the difficulties they have in seeking support.

Published research findings show that young carers may experience a range of different problems and difficulties. These include impaired mental health and emotional difficulties; problems at school caused by trying to balance caring responsibilities and school needs; poor concentration; poor grades and deficiencies in reading and writing ability (see Becker and Leu, 2014). Whilst research has not yet demonstrated a direct causal link between the extent of caring and such problems, it is implicit that such a link exists. However, our findings do not show that an increased level of caring (as seen by a higher MACA score) is associated with a greater likelihood of reporting a mental health problem. Indeed, the opposite was seen for the MACA personal care subscore – a lower score was predictive of reporting a problem, although this effect was small. This may simply be a statistical anomaly; or the skewed MACA scores of the sample may have masked any association that could exist. However, the findings may also suggest that other factors, the context of caring, have an effect on the development of difficulties in young carers and young adult carers. Future research, therefore, needs to explore different factors that influence outcomes for young carers – both exacerbating and mitigating ones. These are likely to include socioeconomic circumstances, family structure, peer support, assessment and support by health and social care professionals, and others. Knowledge of how different circumstances and factors affect outcomes may help to improve support services for young adult carers and to target that support more effectively.

In the logistic regression model, gender and perceived physical health were significant predictors of reporting a mental health problem. A recent survey of mental health in the UK (McManus et al, 2016) has shown that the prevalence of common mental disorders (CMDs) (including anxiety, depression, phobias, obsessive compulsive disorders and panic disorder) is greater in females than in males, and the greatest difference lies within the 16 to 24 age group. In this age group, around 26% of young women were identified as having a CMD compared with 9% of young

men. In our survey of young adult carers, the reporting of mental health problems was greater (47% and 30%) but the sample was much smaller and the responses were based on the answer to a single question. However, our findings do pose the question as to whether the effects of caring, gender and mental health are interrelated, and how. This is a challenge for future research.

The findings presented here do suggest that caring has a direct negative impact on education and on work. A substantial number of days were lost to absence due to caring responsibilities, and many more were compromised because of having to leave early or being called away. This may have serious effects on the young people's abilities to get good grades and progress well through education and into appropriate employment. Once in employment, the caring role interferes with their ability to do their job. The early years of employment are especially important. This is the time when progress is made rapidly and young adult carers appear to be particularly disadvantaged in this respect. Again, context and circumstances may also be important in mitigating or exacerbating the effects of caring. For whilst most researchers report the adverse effects of caring in education, Eley (2003) reported that young carers' schoolwork did not appear to suffer unduly as a result of their caring responsibilities although young people felt that balancing school attendance, homework, and caring obligations could be tiring. The context of caring may again be important in determining the outcomes.

Those at university missed more days than those in any of the other groups. It is possible that young adult carers at different institutions (which have different regulations and requirements) develop different patterns of attendance and absence to cope with caring demands. School absences are likely to be noticed and investigated whilst attendance at university is generally not compulsory so university students can take time off more easily. Similarly, it may be less detrimental for those in work to come in late rather than take whole days off. If absences are not noticed, or they are deliberately concealed, there is the danger that these young people will become 'invisible' – their needs and circumstances will not be recognised and support will not be provided. It is also important not to forget those young adult carers who are not in education, employment or training. Since they are not subject to being absent or late, we could not measure how caring disrupts their lives in a practical sense.

Conclusion

The findings from our survey have highlighted the difficulties faced by young adult carers in terms of their mental and physical difficulties and the impact on their education. In some cases the difficulties faced by the young people appear to be associated directly with the consequences of caring. For example, absence and lateness are related to the extent of caring. However, other aspects of the findings

presented here suggest that there is no simple association between the extent of caring and the reporting of mental health problems. Further research is needed to explore how the circumstances in which caring occurs (for example, family composition, presence of siblings, socio-economic circumstances and the condition of the person being cared for) influence outcomes such as having mental health problems. As we have said at the beginning, young people are involved in providing care in all countries that have been examined. They provide care in many different circumstances and cultural contexts which may all affect outcomes in different ways. For example, Cluver and her colleague's study of children in rural South Africa (Cluver et al, 2012) has shown that children who live in households with parents with AIDS are more likely to experience being hungry at school, missing school and problems with concentration than children from households affected by other illness. Hence, the circumstances or context of caring are important and need to be better understood. In order to provide appropriate and effective support services, more research is especially needed into how the context of caring influences outcomes for these young people. Young adult carers need effective support to ensure they make best use of the opportunities available to them, so as to deliver the positive outcomes they wish for themselves and their families.

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Table 1: MACA total and subscale scores for male and female respondents

	All Respondents (n=270)		Male (n=58)		Female (n=210)		Male vs Female	
MACA Subscale	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**t**	**p**
Domestic	4.42	1.22	4.03	1.24	4.52	1.20	-2.730	.007
Household	3.23	1.04	3.14	1.08	3.26	1.03	-.804	.422
Personal	2.33	2.16	1.83	1.98	2.49	2.19	-2.079	.039
Emotional	4.52	1.36	4.12	1.42	4.62	1.33	-2.511	.013
Sibling	1.81	2.02	1.41	1.62	1.93	2.11	-2.012	.046
Financial/Practical	1.79	1.46	1.71	1.43	1.82	1.48	-.516	.606
Total MACA Score	18.1	5.71	16.24	5.29	18.65	5.73	-2.883	.004

Table 2: Logistic regression predicting the likelihood of reporting a mental health problem

Independent Variable	B	S.E.	Wald	df	*p*	Odds Ratio	95% C.I. for Odds Ratio	
							Lower	Upper
Age	-0.02	0.06	0.16	1	0.687	0.98	0.88	1.09
Gender	0.89	0.38	5.63	1	0.018	2.44	1.17	5.09
Perceived Physical Health	1.37	0.30	21.43	1	0.000	3.94	2.20	7.04
Care for someone with a mental health problem	0.30	0.29	1.12	1	0.290	1.35	0.77	2.37
Care for more than one person	0.42	0.32	1.69	1	0.194	1.52	0.81	2.84
MACA Domestic	-0.25	0.13	3.66	1	0.056	0.77	0.60	1.01
MACA Emotional	0.01	0.12	0.01	1	0.926	1.01	0.79	1.29
MACA Financial & Practical	0.00	0.11	0.00	1	0.977	1.00	0.81	1.24
MACA Household	0.32	0.16	3.76	1	0.052	1.37	1.00	1.89
MACA Personal	-0.20	0.08	7.09	1	0.008	0.82	0.71	0.95
MACA Sibling	-0.09	0.08	1.28	1	0.259	0.91	0.78	1.07
Constant	-0.62	1.13	0.30	1	0.582	0.54		

Table 3: Absence and lateness in the previous two weeks as a consequence of caring

	At School			Sixth form, FE, training			HE College, University			At work		
	Mean	**SD**	**n**	**Mean**	**SD**	**n**	**Mean**	**SD**	**n**	**Mean**	**SD**	**n**
Days missed	0.51	1.14	51	0.97	1.63	61	2.46	3.83	24	0.71	1.16	21
Times had to leave early	0.64	2.03	50	0.89	1.08	63	1.48	2.39	23	0.95	1.99	20
Times called home	0.18	0.56	51	0.46	0.83	61	0.70	2.10	23	0.65	1.27	20
Times late	1.35	2.17	51	1.65	2.60	60	1.30	2.25	23	1.74	3.14	19